PROTOCOL FOR COMMUNITY DEVELOPMENT
Promoting Community Change
for Children with Special Health Care Needs

The goal in promoting community change is to develop self-reliant, self-sustaining community organizations to mobilize local, state and federal resources to improve the quality of life for children with special health care needs and their families. This includes improved community service delivery, development of policies supportive of children and families, and full participation in the life of the community, which nurtures and values all of its members. The community itself is strengthened by recognizing and building upon local community capacities to care for children.

Each community becomes aware of their unique resources and issues impacting children with special health care needs and their families, and purposefully works toward improving the system of care within their community. In so doing, the quality of life is enhanced for all citizens of the community.

The following Protocol for Community Development outlines sequential activities:

1. **Upon Community Selection, Identify and/or Develop Community Group of Investors/Stakeholders**
   Communities may enter the process either through invitation or self-selection. Families, service providers and agencies, community leaders and existing groups are identified. Interest in the Needs-Resource Assessment/Community Development process is ascertained. A relationship is established with either an existing group, or a new group is formed. A team of Parent Community Leaders is identified and placed under contract to serve as liaisons, developers and coordinators of activities and communication.

2. **Conduct Community Needs/Resources Assessment**
   The sponsoring community group/team and Parent Community Leaders plan the needs/resources assessment process. Parents are identified who may serve as surveyors, times and locations for forums noted, and arrangements finalized. Parent and Provider Community Forums are held, interviews and surveys completed and community data compiled. An identification of community resources is integrated into the process, identifying special citizen skills, talents, and knowledge as well as professionals, service organizations, and natural resources.

3. **Data Analysis**
   Information gathered through the Needs/Resources Assessment process is compiled and analyzed by OCSHCN staff, Parent Community Leaders, the Community Planning Team, and System of Care Team/Agency staff. A written Community Report Card, Issues/Things to Consider, and Community Profile is completed. The Workbook for Community Change is updated with specific community documents, identifying resources as well as issues.

4. **Community Presentation of Needs/Resources Assessment Results**
   The results of the Needs/Resources Assessment are presented back to the community according to plans made by the sponsoring community action group. Community team members present the results to the assembled community team

and forks participants, and solicit their participation in taking action. The community team may consist of families who have children with special health care needs, young adults who are disabled, service providers and agencies, advocacy groups, interested community and business leaders, and elected officials.

5. **Community Action**
The community team identifies one or two issues to resolve within a specified - timeframe, and develops a plan of goals and action steps. Parent Community Leaders organize and sustain action to resolve identified issues. The community team pursues all potential resources, intrinsic and financial, to accomplish their goals, continually connecting people and resources with each other, sharing talents and energy. Once substantial progress is made on the initial issues, the community team prioritizes and resolves additional family and community issues for action.

6. **Ongoing Community Support/Increasing Leadership/Linking of Communities**
Parent Community Leaders, through ongoing support and technical assistance by OCSHCN staff and consultant, continually seeks and promotes new community leadership and learning. Linking strategies of regularly held conference calls, get togethers, and conferences assist leaders and members of their respective teams to learn from, coordinate with, and support one another, both from within their own communities and among other communities. Community teams, mentoring other community teams, exchange information and techniques, building statewide strength and power bases to produce both community and state level change.

7. **Measuring Success**
Working in partnership, Parent Leaders, Community Action Teams, and The Office for Children with Special Health Care Needs identity indicators of their success utilizing the *Elements of Community Development* as a guide. Realizing that everything happens through relationships, parent leaders and community team members, are reinforced for their talents, energy and interest in improving the system of care by identifying and recognizing their successes.

8. **State Level Support and Responsibility**
The State Level System of Care Team, through coordination and communication with Parent Leaders and Community Teams, supports community initiatives by identifying system barriers and responsibilities for change, with the goal of promoting desired community change for all children and especially for those with special health care needs.

9. **Transference of Community Development Philosophy and Protocol to other Elements of the Service Delivery System**
Other participants of the system of care are positively influenced and altered through communication and education of the principles, activities and strategies of the Community Development Philosophy and Protocol, thereby promoting a community-based, parent-driven service delivery system.